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September 14, 2022

SUBMITTED ELECTRONICALLY VIA www.cms.gov

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare and Medicaid Services
7500 Security Boulevard Baltimore, MD 21244

RE: Request for Reconsideration of the National Coverage Determination (NCD) for Mobility Assistive Equipment; Pending National Coverage Analysis (NCA) for Power Seat Elevation Systems in Complex Rehabilitation Technology (CRT) wheelchairs [CAG-00461N]

Dear Administrator Brooks-LaSure:

The ALS Association is pleased to provide comments to the Centers for Medicare and Medicaid Services (CMS) in response to the formal request to consider the benefit category and Medicare coverage for seat elevation systems in power wheelchairs and their medical necessity for those living with amyotrophic lateral sclerosis (ALS).

The ALS Association is committed to ensuring that all people with ALS have access to medical equipment that enhances their health and wellbeing and improves their quality of life. Established in 1985, The ALS Association is the only national nonprofit organization fighting ALS on every front. By leading the way in global research, coordinating multidisciplinary care through certified clinical care centers, and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure.

On behalf of the ALS patients and families we serve, we appreciate the opportunity to express our full support for Medicare coverage of power seat elevation systems. We strongly encourage the CMS to move forward in its National Coverage Analysis (NCA) and the Medicare National Coverage Determination (NCD) for seat elevation systems integrated in power wheelchair systems and consider the advantages for the creation of a new benefit category and coverage for this mobility enhancing and medically necessary technology.

People with ALS are eligible for Medicare based on age or disability and have complex medical needs which include the need to access power wheelchairs with seat elevation systems as a **medical necessity**. According to a 2021 ALS FOCUS [survey](#) of people living with ALS and their caregivers, 53 percent of those surveyed needed power wheelchairs and their related seat elevation accessories for mobility purposes. However, affordability remains a barrier to equitable access of these technologies. While insurance may cover a portion of the cost of a power wheelchair, only 4 percent of ALS patients surveyed stated that insurance paid a portion of the cost of their seat elevation feature. Therefore, although qualified clinicians often recommend seat elevation, cost remains a significant barrier to supply medically necessary seat elevation systems to people living with ALS.

The ALS community values Medicare coverage of durable medical equipment and especially access to medically necessary technologies for people living with ALS. In accordance with the purpose expressed



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for this National Coverage Analysis (NCA), The ALS Association agrees with the consensus of the disability community and other stakeholders that power seat elevation systems integrated in power wheelchair systems are a medically necessary safety feature since they are specifically employed in the performance of non-level transfers as a medical function and are useful in performing other medically necessary purposes such as assisting with activities of daily living (ADLs).

Currently, most Medicare beneficiaries with ALS must forgo medically necessary power wheelchair seat elevation systems. As identified by the National Council on Disabilities, wheelchair users without access to these features and systems have and will continue to be harmed by potentially preventable medical complications such as musculoskeletal overuse injuries (e.g., neck and shoulder), increased pain, difficulty transferring for key ADLs. For people living with ALS, seat elevation in their power wheelchair is a medically necessity rather than a convenience.

As one person living with ALS explained: "With seat elevation, I can transfer myself on and off the toilet. That means my wife, or my child does not have to come and lift me from my chair onto and off the toilet. When someone must help me on and off the toilet and with other activities, I need a full-time caregiver which is a significant cost for me and my family. A modest investment by Medicare in seat elevation would mean I would need less paid and family help and that is extremely important to me."

Access to seat elevation systems in power wheelchairs allows a person living with ALS greater independence, improves their self-care confidence, increases their ability to complete mobile activities of daily living, and most importantly, ensures safe transfers from a wheelchair to the toilet, bed, chair, or vehicle which decreases fall risks, reduces physical injuries, and potentially avoids unplanned emergency room visits and hospitalizations. Power elevation systems on wheelchairs enable people living with ALS to be less dependent on caregivers and employ greater freedom to enjoy their quality of life. However, without access to these mobility systems, people living with ALS may decline more rapidly, become confined to their beds, and unable to perform mobility related activities of daily living in their homes which takes a toll physically and mentally.

For the purposes of these comments, we have listed categories that we identified as valuable to those living with ALS.

Ensuring health and safety:

Seat elevation systems can be effective at reducing fall related injuries and ensure a higher probability of a safe transfer.

Seat elevation system on a power wheelchair increases the safety of transfers for people living with ALS and for their caregivers. The risk of a patient falling while moving or being moved between a power wheelchair and their bed, toilet, car, or other chair significantly decreases when they can transfer to and from equal height surfaces. A person living with ALS can also reduce the risk of falls by employing a seat elevation system to reach an item that is beyond their reach. Falling out of a wheelchair is extremely dangerous for someone who has reduced mobility and function of their upper and lower extremities. In addition to potentially hitting their head or incurring another injury, someone who falls from their power wheelchair could be in great danger because they cannot move. Falls also threaten the health and wellbeing of someone who has ventilation device and could compromise their breathing if their ventilator malfunctions or becomes disconnected, or if their chest compresses and they are unable to move.

Assist with activities of daily living (ADL):

Seat elevation systems allow a person living with ALS to complete activities of daily living independently. ADLs are medically necessary to manage one's basic physical needs, including personal hygiene or grooming, dressing, toileting, transferring or ambulating, and eating. Also, enabling a person living with

ALS to increase their performance of ADLs can have additional medical benefits by contributing to improved heart and lung function, increased bone strength, and improved joint mobility, bladder function, muscle strength, and improved mental wellbeing.

Promotes good mental health and quality of life:

Seat elevation can promote good mental health for a variety of reasons. It would allow someone in a wheelchair to be on the same level as the person they are communicating with, so they are heard and seen by the other person. People with ALS also express the need to remain independent for as long as possible, to remain in their homes, and be able to care for themselves, which promotes a better quality of life and may lower risks or levels of depression commonly experienced by these patients.

Supports and protects the welfare of paid and family caregivers:

ALS patients who require caregiver assistance to transfer to bed or other surfaces would benefit from a power wheelchair with seat elevation. Transfers that involve vertical as well as lateral movement are physically taxing for both the patient and caregiver. Decreasing the need for vertical movement by making the wheelchair seat height level with the transfer surface results in a safer transfer and reduces the risk of injury to both the patient and the caregiver.

About ALS:

ALS is a progressive neurodegenerative disease that destroys nerve cells in the brain and spinal cord, causing the loss of muscle control throughout the body. People with ALS become prisoners within their own bodies, unable to eat, breathe, or move on their own. Their minds, however, often remain sharp so they are aware of what is happening to them. There is no cure for ALS, and most people with the disease die within 2 – 5 years of diagnosis. For unknown reasons, veterans are twice as likely to develop ALS as the general population. About 90 to 95 percent of ALS cases are sporadic, meaning they are not inherited. An estimated 5 to 10 percent of ALS is familial and caused by mutations in genes. Although the disease can strike at any age, symptoms most commonly develop between the ages of 55 and 75. Until we cure ALS, our goal is to make ALS a livable disease for all and that will require both integrated care delivery services and access to innovative mobility systems.

ALS often commences with muscle twitching and weakness in one leg, one hand, the face, or the tongue. The weakness slowly spreads to both arms and both legs as the motor neurons slowly die and stop sending signals to the muscles which results in the loss of the use of a limb and slurred speech. Eventually, ALS affects major muscles essential to move, speak, eat, and breathe. As the disease progresses, a person with ALS requires more support for activities of daily living, including eating, walking, using the toilet, personal hygiene, dressing, and transferring in and out of bed or a chair. Caregiving support, provided either by family members or paid caregivers, is necessary to assist someone who has lost the ability to ambulate on their own. In addition to skilled and non-skilled nursing care provided by paid and family caregivers, a person living with ALS often requires durable medical equipment to manage their conditions such as complex power wheelchair systems, ventilators, speech generating devices, and other assistive technologies.

Conclusion:

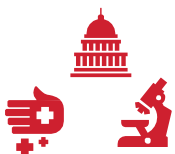
Seat elevation systems integrated in power wheelchairs provide medically necessary benefits for people living with ALS. Decreased risk of falls and injuries, neck and back muscle pain reduction, increased independence, enhanced mobility of reaching elevated surfaces and items, less reliance on personal assistance, and additional safety features afforded by these systems protects the wellbeing of the power wheelchair user and their caregivers.

The ALS Association strongly urges CMS to prioritize the expansion of coverage for seat elevation systems in power wheelchair systems through its National Coverage Determination (NCD) for the Medicare Program.

Please contact Rich Brennan, Vice President of Federal Affairs, rich.brennan@als.org with any questions.
Sincerely,

A handwritten signature in blue ink that reads "Neil Thakur". The signature is fluid and cursive, with the first name "Neil" being larger and more prominent than the last name "Thakur".

Neil Thakur, Ph.D.
Chief Mission Officer
The ALS Association



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